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Nurses' knowledge, attitudes, and willingness to interact with clients with acquired immune deficiency syndrome

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**Nurses' knowledge, attitudes, and willingness to interact with
clients with Acquired Immune Deficiency Syndrome**

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San Jose State University, 1989

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NURSES' KNOWLEDGE, ATTITUDES, AND WILLINGNESS
TO INTERACT WITH CLIENTS WITH
ACQUIRED IMMUNE DEFICIENCY SYNDROME

A Thesis

Presented to

The Faculty of the Department of Nursing
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In Partial Fulfillment
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Master of Science

By

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ABSTRACT

NURSES' KNOWLEDGE, ATTITUDES, AND WILLINGNESS TO INTERACT WITH CLIENTS WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME

by Patti Emmett

Little is known about the correlates which may influence the behavior of health care workers toward clients with AIDS. This non-experimental, correlational survey was guided by Rogers' Life Process Model of Nursing. It examined nurses' knowledge, attitudes, and willingness to interact with clients with AIDS. The purpose of this research was to explore the strength and direction of correlations between these variables using Pearson's r .

An anonymous questionnaire containing a demographic survey, knowledge test, vignette, Prejudicial Evaluation and Social Interaction Scales was distributed to 397 nurses within a selected community hospital in northern California; 224 were returned.

Positive correlations were found between attitudes and willingness ($r = .73$, $p < .01$) and between knowledge plus attitudes and willingness ($r = .45$, $p < .05$). However, knowledge about AIDS did not significantly correlate with willingness. AIDS education may increase nurses' willingness to care for clients with AIDS when attitudes related to AIDS are included in nursing education curricula.

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Chapter 1

INTRODUCTION

Acquired Immune Deficiency Syndrome (AIDS) is a viral infection of humans which causes a severe immunodeficiency. AIDS is caused by a human retrovirus which has been named the Human Immunodeficiency Virus (HIV). The clinical spectrum of AIDS virus infection varies and is often progressive. The majority of HIV infected individuals are asymptomatic but do demonstrate non-protective antibodies to the AIDS virus in their blood (Centers for Disease Control, 1985). A second phase of this spectrum occurs when the infected individual becomes symptomatic with a constellation of symptoms that can include fevers, night sweats, lymphadenopathy, anorexia, diarrhea, weight loss, and fatigue (Benenson, 1985, p. 2). This constellation of symptoms is known as AIDS Related Complex (ARC) (Centers for Disease Control, 1984). In the third phase, the individual with AIDS progresses to develop severe immunodeficiency which allows a syndrome of opportunistic infection, cancers, and/or a wasting syndrome to occur (Centers for Disease Control, 1987). Individuals with these full manifestations of HIV infection represent the smallest proportion of HIV infected individuals. Yet, to date, the number of individuals with AIDS in the United States is nearly 70,000. And by the year 1991, the Surgeon General estimates that 270,000 individuals will have developed the full manifestation

of HIV infection known as AIDS (Koop, 1986).

In the United States, cases of AIDS have occurred primarily in gay and bisexual men and intravenous drug users (Centers for Disease Control, 1984). In addition, AIDS is slowly disabling and eventually is fatal. Although infection with the AIDS virus may be prevented through education and behavior changes (Koop, 1986), educational discussions about AIDS involve topics of death, homosexuality, intravenous drug use, and fatal communicable disease. As members of the general community, nurses are susceptible to the influences of many kinds of stereotypes and biases held by the people within their community (Kelly, St. Lawrence, Smith, Hood, & Cook, 1987). If nurses adopt stereotypical and biased beliefs, negative attitudes may follow (Fishbein & Ajzen, 1975, p.15). These attitudes may influence their professional relationships with clients. The purpose of this research study is to explore nurses' knowledge, attitudes, and willingness to interact with clients with AIDS. In addition, this research study aims to clarify the importance of exploring the nurses' attitudes about AIDS and people with AIDS when providing effective AIDS education to nurses. Appropriately designed AIDS education for nurses may contribute towards a decreased incidence in the frequency of treatment refusal by nurses to care for clients with AIDS.

Problem and Research Question

Epidemics of communicable disease have historically elicited misunderstanding and fear (Marks & Beatty, 1976, p. 24). Fear of the unknown has been prevalent since the onset of the AIDS epidemic. "If the illness is a serious one, fears escalate as the illness comes closer. Knowing the cause of an illness or its mode of transmission provides some rational approach to interrupting the spread of the disease" (Musto, 1986, p. 97).

An example of this fear is the proposal to quarantine those with AIDS. Although the causative agent and mode of transmission for AIDS are now known, quarantine is still proposed by some. However, quarantine is an irrational, fear-based approach to preventing infection with HIV based upon known information about transmission through sexual, parenteral, and perinatal routes (Centers for Disease Control, 1987). Such fears may be barriers to adequate, competent care for clients with AIDS.

Another source of fear is the prevalence of the disease among gay and bisexual men. The AIDS epidemic has suddenly faced members of society with their own fears of homosexuality (homophobia) (Scheitinger, 1986). Homosexuality may be seen as a challenge to the natural order of the family, procreative sex, and conventional definitions of gender. Reactions to homosexuality may include disapproval, fear, and suspicion (Elford, 1987).

Nurses, as members of society may also be faced with their own fears of homosexuality (known or unknown) of in interacting with gay and bisexual clients.

One of the oldest, most commonly held societal beliefs since the plagues of Pharaoh in 1495 BC is that infections are sent by God to punish sinners (Marks & Beatty, 1976, p. 24). When AIDS was first reported in Los Angeles in 1981, it occurred in gay men (Centers for Disease Control, 1984). The press and the public have focused upon gay men even though the infection occurs in heterosexuals as well. AIDS has even been seen by some as a fair, divine punishment for a life-style considered by some to be deviant (Elford, 1987). Like epidemics of prior eras, AIDS has been linked to morality and blame. AIDS is identified with "those whose sexual practices and the use of drugs place them outside the mainstream" (Bayer, 1986, p. 169).

Also, "the cumulative incidence of AIDS cases is disproportionately high among blacks (3.0 to 1) and Hispanics (2.6 to 1) compared to whites" (Centers for Disease Control, 1987, p. 10). This high incidence among these minority populations provides two additional targets for potential discrimination (Bayer, 1986). Nurses may be prepared to provide care for people from culturally diverse backgrounds but may not be as prepared to care for clients with diverse sexual orientations (Bolle, 1988).

Fear of contagion and death emerge as the

transmissibility of epidemic infection becomes evident. In the absence of a preventive vaccine and no cure, the situation may be perceived by society as out of control (Elford, 1987). In the "presence of uncertainty and potential chaos, people fall back on an earlier set of beliefs" (Elford, 1987) which frequently set apart the infected population as undesirable, contaminated, and outside the norm. Preoccupation by society and health care providers with casual contact transmission may represent a belief that control is lost. Society and health care providers may perceive that self-protective rituals are needed to keep the pollutant away in order to restore organization from the seeming chaos (Elford, 1987). Nurses are presented with the daily challenge of overcoming their fear of contagion and death when interacting with and caring for clients with AIDS.

Thus far, some specific sources of fear and negative attitudes toward those with AIDS have been identified. If such fears and attitudes occur among nurses, they may influence the nurses' ability to provide care. However, a gap in knowledge exists regarding the factors which may impact upon the nurses' willingness to interact and provide care to the client with AIDS. Little is known about the possible correlates of health care workers which may influence their behavior towards clients with AIDS, or their outright refusal to care for clients with AIDS.

This study aims to explore the possible correlation among these three variables: (a) nurses' knowledge regarding AIDS, (b) nurses' attitudes regarding AIDS, and (c) nurses' willingness to interact with and provide care for clients with AIDS. The broader goals of this study are to gain increased understanding of some of the characteristics which may contribute to the occurrence of treatment refusals by health care workers when presented with a client with AIDS, to understand some of the factors which may better prepare the nurse to be more willing to provide care to clients with AIDS, and to identify additional subjects appropriate for nursing education which, indirectly, can improve care delivered to clients with AIDS.

Hypotheses

In order to explore relationships among the study variables, the following hypotheses were analyzed. The hypotheses examine whether nurses who have more knowledge about AIDS will be more willing to interact with clients with AIDS. The hypotheses also examine whether nurses who have more positive attitudes regarding AIDS will be more willing to interact with clients with AIDS. Finally, the hypotheses examine whether nurses who have more knowledge and more positive attitudes about AIDS will be more willing to interact with clients with AIDS.

H₁ : The greater the nurses' knowledge about AIDS, the greater the nurses' willingness to interact with clients

with AIDS.

H₂ : The greater the nurses' positive attitude about AIDS, the greater the nurses' willingness to interact with clients with AIDS.

H₃ : The greater the nurses' knowledge and positive attitude about AIDS, the greater the nurses' willingness to interact with clients with AIDS.

Purpose and Need

The purpose of this study is to explore possible correlations between the nurses' knowledge, attitude, and the nurses' willingness to interact and provide care for the client with AIDS. Currently, a gap in the knowledge exists regarding such factors while reactions of mild anxiety to treatment refusal among physician, nursing, laboratory, and other hospital personnel continues to be documented (Banning, 1988). Understanding some of the factors which may contribute to the occurrence of treatment refusals by health care workers when presented with a client with AIDS may help to decrease such incidents in the future. An understanding of factors which may better prepare the nurse to be more willing to provide care to clients with AIDS is beneficial to the clients with AIDS as they can be extremely dependent upon nursing care in the hospital or community setting. Finally, identification of additional subjects appropriate for nursing education can indirectly improve care delivered to clients with AIDS.

Definition of Terms

For the purposes of this study, the following definitions will be used:

1. Knowledge is the clear and certain perception of truths and facts (Thatcher, 1921, p. 473).
2. Attitude is a learned predisposition to respond in a consistently favorable or unfavorable manner and a major determinate of the subject's intention to perform the behavior in question (Fishbein & Ajzen, 1975, p. 15).
3. Willingness to interact is the subject's intention to engage in behaviors involving verbal, visual, or tactile contact (Fishbein & Ajzen, 1975, p. 17).
4. Human Immunodeficiency Virus (HIV) is the etiologic agent of Acquired Immunodeficiency Syndrome and is classified as a human retrovirus (Lewis, 1988, p. 4).
5. Antibodies are proteins of human serum produced in specific response to a foreign substance known as an antigen, e.g. HIV (Barrett, 1980, p. 288).
6. Acquired Immunodeficiency Syndrome (AIDS) is the syndrome resulting from infection with HIV which is characterized by opportunistic infections, cancers and/or a wasting syndrome in an individual who has undergone a severe loss of immune function (Lewis, 1988, p. 4). (See Appendix C for the complete Revised Centers For Disease Control Case Definition of AIDS, 1987, from which Lewis derived this definition).

7. Health care workers are professional direct care providers (e.g. nurses and physicians), nonprofessional direct care providers (e.g. aides and orderlies), and indirect care providers (e.g. housekeepers and clerical staff) (Lewis, 1988, p. 277).

Research Design

This study uses a non-experimental research design in that it attempts to find meaning in observable phenomena without manipulating the independent variables (Lo-Biondo-Wood & Haber, 1986, p. 129). This correlational design examines three independent variables; (a) nurses' knowledge, (b) nurses' attitudes, and (c) nurses' knowledge plus attitudes, with one dependent variable; (c) nurses' willingness to interact with and care for clients with AIDS. The purpose of this study is to explore nurses' knowledge, attitudes, and willingness to interact with clients with AIDS. In addition, this research study aims to clarify the importance of exploring the nurses' attitudes about AIDS and people with AIDS when providing effective AIDS education to nurses. This study aims to examine the factors which may contribute toward improved AIDS education for nurses. Appropriately designed AIDS education for nurses may contribute towards a decreased incidence in treatment refusal by nurses when presented with the client with AIDS in the hospital or community setting.

Voluntary participation in this study was offered to

all 397 registered or licensed vocational nurses employed in a nonprofit, private, 214 bed, community, nonteaching hospital in northern California.

Data collection was achieved through distribution of a five part survey questionnaire. Each potential subject was asked to anonymously complete and return the survey questionnaires via the hospital courier system to the hospital's Education Department where they were collected.

The survey questionnaire asked the participant for demographic data (see Appendix B). The first variable, knowledge, was measured by a ten-question tool used by the San Francisco AIDS Foundation (1986) (see Appendix B). Participants were next asked to read a case vignette. The second variable, attitudes, was measured by a 12-item Prejudicial Evaluation Scale (Kelly et al. 1987) which participants answered using information provided in the case vignette (see Appendix B). Willingness to interact with and care for clients with AIDS was measured using the seven-item Social Interaction Scale (Kelly et al. 1987) which participants answered using information provided in the case vignette (see Appendix B).

This non-experimental design contains three independent variables (nurses' knowledge, nurses' attitudes, and nurses' knowledge plus attitudes about AIDS) and one dependent variable of nurses' willingness to interact with and care for the client with AIDS. In order to determine if nurses'

knowledge or attitudes, or both, are related to nurses' willingness to interact with the client with AIDS, Pearson's product moment correlation coefficient was computed. This correlation was computed to discover if significant correlations exist between the variables of nurses' knowledge and their willingness to interact with clients with AIDS, nurses' attitudes and their willingness to interact with clients with AIDS, and nurses' knowledge and attitudes and their willingness to interact with clients with AIDS. Data from registered nurse respondents was tabulated separately from licensed vocational nurse respondents. Since no statistically significant difference was found between registered nurse and licensed vocational nurse means for knowledge, attitudes, and willingness to interact instruments, the data from these two groups was combined.

Scope and Limitations

This study is limited by sample population, data collection method, the instruments, and the design. The sample is limited to an accessible, voluntary, convenience group of employed registered and licensed vocational nurses in a small, private, nonprofit, nonteaching community hospital.

The study's non-experimental design does not eliminate the possible effects of uncontrolled, intervening variables. Subjects within the institution may behave so as to provide

socially desirable answers even though anonymity is provided.

Finally, the correlational design does not allow for cause and effect conclusions. In fact, the willingness to interact with clients may influence nurses' attitudes towards them.

Finally, generalization of the results of this study are limited to registered and licensed vocational nurses employed in this community hospital. However, study results may have implications for registered and licensed vocational nurses of hospitals of similar size and demographic characteristics.

Chapter 2
CONCEPTUAL FRAMEWORK AND
REVIEW OF RELATED LITERATURE

Conceptual Framework

The conceptual framework for this study is provided by Martha Rogers' Life Process Model of Nursing. Martha Rogers presented her conceptual model of nursing in An Introduction To The Theoretical Basis Of Nursing (1970). She further refined her conceptual model in "Nursing: A Science of Unitary Man" (1980).

Rogers presented man as the center of nursing's focus. In this research problem, the central focus is represented by the client with AIDS experiencing hospitalization within the community hospital setting. Nursing's goal is to provide nursing care which is equivalent in all aspects to the care given to all non-AIDS clients in a manner which is equally safe for the health care worker. Rogers conceptualized man as resonant, or interactive, with the environment (1970). Rogers portrayal of man's interactions with the environment is rooted in nursing science and her model is categorized as energy field. She defined resonancy as a continuous change from lower to higher frequency wave patterns in both the human and environmental fields (Rogers, 1980). In this research problem, the client with AIDS interacts with the nurse within the hospital setting. This study acknowledges the potential influence of the nurse's

preexisting attitudes and knowledge concerning AIDS upon the interactions between the nurse and the client with AIDS. Nurse anxiety and the delivery of inconsistent care to clients with AIDS have been documented by Brock (1986).

Rogers further conceptualized man's interactions with the environment as an evolving and changing process which occurs over space-time (Marriner, 1986, p. 347). Rogers termed this principle as helicy and described helicy as dynamic, diverse, non-repeating rhythmicities (1970). This ongoing process is conceptualized as spiralling about a "longitudinal axis bound in space-time" (Mariner, 1986, p. 347). This image is consistent with the evolving and developing knowledge and attitudes of the nurse regarding clients with AIDS. This image is also applicable to the evolving and developing knowledge and attitudes of the client about the diagnosis of AIDS and the experience of chronic infection over space-time, from diagnosis to death.

The nurse reacts to the client with AIDS just as the client with AIDS reacts to the nurse. Rogers (1970) termed such interpersonal interactions as synchrony. Rogers defined synchrony as the change in human energy field which is dependent upon the state of human and environmental fields at any given point in space-time (1970). The quality of the synchrony with the nurse-client interaction may affect the nursing care delivered to clients with AIDS, particularly if a lack of knowledge about AIDS or harsh

attitudes are present (Brock, 1986).

This research problem, guided by Rogers' Life Process Model of Nursing, explores nurses' knowledge, attitudes, and willingness to interact with and care for clients with AIDS.

Related Literature

Epidemics of communicable disease have historically elicited misunderstanding and fear. In an analysis of human behavior during epidemics, McNeill (1976, p. 126) noted that customary restraints exercised by communities broke down and rituals and bizarre behavior arose which were based in anxiety and panic. "Like other major epidemics in history, AIDS is also associated with a high mortality rate, creating a tremendous amount of stress for the deliverers of care" (Bolle, 1988, p. 843).

The Centers for Disease Control reported that the first cases of AIDS occurred as early as 1981 (Centers for Disease Control, 1984). However, three years later, Rosendorf and Hatfield (1984) analyzed the behavior of health care workers in response to AIDS as not unlike behavior noted in times of pestilential contagion. And though the etiologic agent of AIDS was discovered in 1984, a survey by Rosse (1984) of psychiatric staff done that same year demonstrated high levels of anxiety toward clients with AIDS. Rosse also showed a relationship between fear of contracting AIDS and the belief in the "possible easy communicability of the disorder" (p. 523).

Fear among health care workers became a growing problem within health care institutions. Providers discarded pens and other equipment touched by clients with AIDS, insisted upon unnecessary quarantines of AIDS clients to their hospital rooms, and refused to perform autopsies on those who died from AIDS (Adams & Lowy, 1985). In a survey by Moriarty (1988), three out of four nurses replied that they would refuse to provide care to clients with AIDS in certain circumstances, but not to clients with other potentially fatal communicable diseases. The high mortality of AIDS and its epidemic increase in incidence have evoked strong feelings of fear and avoidance (Krener, 1986). This analysis pointed out that nurses use healthy denial to work among ill patients. However, the ability to deny is threatened by the unequivocally fatal outcome of AIDS. (Krener, 1986).

The need for an "educational blitz" to reduce the fear of AIDS among hospital staff was identified (Banning, 1985, p. 10). Educational programs began in earnest to deal with the needs of health care workers during 1986. McCutchan argued that health care workers would have to confront their own fears. "If you simply present the facts...without giving people a chance to ventilate their fears, you leave them well-informed but fearful people" (1986, p. 19). He stated that there is no moral issue attached to a viral infection but rather misconceptions about homosexuality,

drug use and sexually-transmitted disease (1986).

Knowledge, attitudes, and behaviors of health care workers in relation to AIDS was studied by Searle (1987). This study identified fearful and avoidance behaviors by health care providers toward clients with AIDS. Examples of fearful behavior identified included the use of space suits by ambulance personnel, refusal to provide care by general practitioners and dentists when a client's positive HIV antibody status was known, surgeons' and anesthesiologists' reluctance to perform lung biopsies, and refusal by pathologists to handle specimens or do necropsies. Further, although many nurses have reacted with intense commitment in caring for clients with AIDS, others have not (Searle, 1987). As an explanation, Searle's study suggested an identified lack of knowledge concerning the basic concepts surrounding HIV infection among physician and nurse subjects (1987). Searle's study conducted in London, England identified fearful behavior towards clients with AIDS. Therefore, this behavior was not limited to the United States.

The attitudes of health care workers toward clients with AIDS, cancer, diabetes, and heart disease were studied by Katz, Hass, Parisi, Astone, and McEvaddy (1987). Subjects of this study included college students, hospital nurses, medical students, and chiropractic students. The study measured moral worth, competence, dependence,

depression, and morbidity perceptions. All subject groups rated the clients with AIDS the lowest in competence and moral worth. More than any other group, AIDS patients were seen as responsible for their illness. Kennedy (1987) reiterates the comments of McClutchan (1986) that health care workers must confront their own fears before they can support a client with AIDS. Kennedy cites ongoing claims that AIDS is God's punishment to homosexuals. She suggests that nurses may benefit from exploration of their own attitudes towards clients with AIDS as a worthwhile part of their AIDS education. Education for nurses about AIDS which deals with both health care worker knowledge and health care worker attitude is currently under pursuit at the City of Hope National Medical Center (Kennedy, 1987).

Finally, a study of physician subjects selected from large cities in three states with midrange state prevalence for AIDS forms the major reference for this research design (Kelly, St. Lawrence, Smith, Hood & Cook, 1987). Subjects read one of two identical vignettes describing a client with the diagnosis of leukemia or AIDS. Responses to the vignettes were measured using a Prejudicial Evaluation Scale constructed specifically for this study, the Social Interaction Scale which examined the willingness to interact with the client with AIDS, and the Interpersonal Evaluation Inventory. Results of this study showed negative attitude bias among selected physicians toward clients with AIDS. In

addition, physician subjects were much less willing to interact with the client with AIDS than the client with leukemia, even though none of the interactions described would carry any risk for HIV transmission. Thus, the study suggests that significant differences in physician responses were attributable to the diagnoses since the vignettes were identical in every other way (Kelly, et al, 1987).

Summary

Lack of knowledge, the presence of fear, and attitude bias have previously been demonstrated in health care workers. Willingness to interact has also been shown to decrease when clients have a diagnosis of AIDS. However, the relationship of the study variables, knowledge and attitudes regarding AIDS and the willingness to interact with the client with AIDS has not been specifically studied among health care workers. An improved understanding of the relationships among these variables would benefit AIDS clients through application to nursing education and improved nursing care.

Chapter 3

THE METHOD

The following chapter includes a discussion of the design and methodology of this study in order to investigate the relationships, if any, between nurses' knowledge and/or attitudes, and willingness to interact with and care for clients with AIDS. This research will add to the body of nursing knowledge concerning nurses' willingness to provide or refuse care to clients with AIDS.

Research Design

This study uses a non-experimental, correlational, survey design as no variables were manipulated by the researcher. Correlations were analyzed to estimate the strength and direction of any relationship which may exist between the variables. A survey method was selected for this design as an efficient way to gather data which could only be provided by individual subjects (Lo-Biondo-Woods & Haber, 1986, p. 144). Because the study measured attitudes about AIDS as well as willingness to care for clients with AIDS, written anonymous survey rather than verbal reporting was utilized to diminish social desirability as a source of inaccuracy (Lo-Biondo-Wood & Haber, 1986, p. 160). The assessment of the subject's knowledge involved questions with correct or incorrect responses which could be provided at the pace most comfortable to the subject. Therefore, knowledge was most efficiently measured using structured, self-paced,

fixed-response items in the form of a written survey (Lo-Biondo-Wood & Haber, 1986, p. 160).

Subjects and Setting

The targeted population (397) consisted of the entire registered and licensed vocational nurse population employed at a selected hospital. This hospital is located in a coastal community characterized by a tourist economy in a rural geographic setting in northern California. The hospital serves a largely affluent, elderly community population which, for the most part, lacks cultural diversity.

Subjects who received survey questionnaires were employed in the following areas of nursing practice: medical-surgical, maternal-child, pediatrics, intensive coronary care, cardiac telemetry, emergency, surgery, outpatient surgery, short stay care, chemical dependency, oncology, administration, education, hemodialysis, radiation therapy, outpatient immunology services, and a medical-surgical unit which cared primarily for clients hospitalized with AIDS.

Data Collection

After obtaining institutional permission and Human Subjects Review permission for this research, data collection was achieved by the use of an anonymous survey questionnaire. Names and departments of all hospital licensed vocational and registered nurses were obtained from a cardiopulmonary

resuscitation certification listing maintained by the hospital.

Survey questionnaires (397) were hand delivered to the communication folders of all subjects on their respective hospital units. Constancy in data collection was maintained by distributing the instrument to all 397 subjects over a two day period. Subjects were instructed to return completed questionnaires within two weeks. Subjects were provided with a return envelope addressed with the investigator's name and location. Subjects were instructed to return completed survey questionnaires within the hospital to the Education Department, where they were collected by the investigator. Because assured anonymity seemed essential for candid questionnaire responses, no effort was made to identify and contact non-responders.

Instruments and Measurement

The survey questionnaire included a demographic data sheet and an instrument measuring each of the three variables; knowledge, attitude, and willingness to interact with clients with AIDS. The five page survey questionnaire required approximately ten minutes to complete. Part one of the survey questionnaire requested demographic information about the subject as follows: (a) age group (20-29, 30-39, 40-49, 50-59, 60 or older), (b) sex (female or male), (c) years of nursing experience (0-4, 5-9, 10-14, 15-19, 20-24, 25-29, 30-34, 35-39, 40 or more years), (d) education (LVN,

RN, associate degree, bachelor's degree, master's degree, doctorate degree), and (e) previous experience, if any, with HIV-positive individuals (none, 1-4, 5-9, 10-14, 15-19, 20-24, 25 or more individuals) (see Appendix B).

Knowledge

Part two of the instrument contained a 10-item, true or false response test which measured nurses' knowledge concerning AIDS. The test was developed by the San Francisco AIDS Foundation and was titled "Facts vs. Fiction: What Everyone Should Know About AIDS" (San Francisco AIDS Foundation, 1986). Two test items were modified to avoid negatively phrased items which, in using the test on 62 subjects in its original format, yielded low scores (see Appendix B). Each item was assigned one point. Correct responses were summed to provide the knowledge score. Ten total points were possible (1 point, 10 items). Items which were not attempted were scored as incorrect answers.

Attitudes

Next, subjects were asked to read a 100-word vignette and two inventories on which impressions of the person described in the vignette (Mark) were recorded. The case vignette (part three of the instrument) (Kelly et al., 1987) read by each subject described Mark as a college graduate employed in management in a computer firm. Mark was portrayed as outgoing, with athletic pursuits. The second paragraph of the vignette described the onset of Mark's

decline in health and eventual diagnosis of AIDS. Mark's long-standing romantic partner (no sex was given) was described as initially drawn closer to Mark, but later his partner became emotionally distant and incapable of coping with Mark's life-threatening illness (see Appendix B).

Part four of the instrument contained a 12-item Prejudicial Evaluation Scale developed by Kelly et al. (1987) (see Appendix B). The Prejudicial Evaluation Scale was adapted by Kelly et al. from previous research which assessed interpersonal judgments of victims, and anecdotal reports from AIDS victims which described the negative attitudes they had encountered. This scale was used by Kelly et al. to study stigmatization of AIDS patients by physicians (1987). As used in this study, items measured attitude prejudice toward the portrayed client with AIDS. Each item was rated on a five-point Likert scale (one = strongly disagree/harsh attitude to five = strongly agree/supportive attitude). Responses were summed to provide the score. Sixty total points were possible (five points, 12 items). Items which were not attempted earned zero points.

Willingness To Interact

Finally, part five of the instrument contained a seven-item Social Interaction Scale also developed by Kelly et al. (1987) (see Appendix B). This scale was used by Kelly et al. to measure physicians' willingness to interact in routine social/conversational settings with individuals with

AIDS. This scale also refers to the vignette above. Items measured willingness to interact with the portrayed client with AIDS in a variety of interactive settings. Each item was rated on a five-point Likert scale (one = strongly disagree/unwilling to interact to five = strongly agree/willing to interact). Responses were summed to provide the willingness to interact score. Items which were not attempted earned zero points. Thirty-five points were possible (five points, seven items).

Analysis

The method of analysis for this non-experimental correlational design was a Pearson's product moment correlation coefficient (Pearson's r). The correlation between the independent x variable of nurses' knowledge and the dependent y variable of nurses' willingness to interact and care for clients with AIDS was examined. In addition, the correlation between the other independent x variable, nurses' attitudes, and the y variable of nurses' willingness to interact with and care for clients with AIDS was examined. Finally, the correlation between nurses' knowledge and attitude added together as the independent x variable and the dependent y variable of nurses' willingness to interact with and care for clients with AIDS was examined. Correlations were examined for a significant difference from zero. The calculated value of r was converted to a t value by using a conversion formula (Weinberg & Schumaker, 1974)

where the t value has $n - 2$ degrees of freedom. Correlations were considered significant at the .05 level if the t value exceeded the value located at the intersection in the t distribution table (Weinberg & Schumaker, 1974, p. 298)

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

The findings and analysis of the survey questionnaire data concerning nurses' knowledge, attitudes, and willingness to interact with and care for clients with AIDS are described in this chapter. Demographic characteristics of the sample population (respondents), and relationships among the knowledge, attitude, and willingness to interact variables are presented.

Description of the Sample Population

Of the 397 survey questionnaires which were distributed, 224 were returned. Scores for the three variables of (a) knowledge (b) attitudes, and (c) willingness to interact were tabulated separately for the LVN and RN respondents. Because no significant difference was found between the mean scores for these three variables for the 19 LVN respondents when compared to the 203 RN respondents (two did not indicate LVN or RN status), LVN and RN data were grouped together. The rate of return for the 224 usable survey questionnaires was 56.4%.

Age, Sex, Nursing Experience, and Education

Part one of the data collection instrument asked for demographic variables. Tables 1 - 4 represent the numbers and percentages of the respondents according to age, sex, nursing experience, and education.

Age of the respondents is presented in Table 1. Age of

the respondents ranged from 20 to 60 or older. The mean age was 39.6 years.

Table 2 represents the numbers and percentages of the respondents according to sex. Seven (3.1%) of the respondents were male while the majority (96.5%) were female. One respondent (0.4%) did not indicate a response. Table 3 represents the numbers and percentages of respondents according to years of nursing experience. The experience ranged from zero to over 40 years, with the most common level of experience being 10 - 14 years (24.6%). The second most common level of experience was 15 - 19 years (20.5%). The mean years of experience was 15.3 years for the 224 respondents.

Table 4 represents the number and percentages of respondents according to the highest level of education. Eleven held LVN licensure (4.9%), 36 were diploma RNs (16.1%), 8 LVNs held associate degrees (3.6%), 76 RNs held associate degrees (33.9%), 1 LVN held a baccalaureate degree (0.4%), 76 RNs held baccalaureate degrees (33.9%), and 14 RNs held master's degrees (6.3%). Two of the respondents (0.9%) did not indicate a response.

Table 5 represents the numbers and percentages of respondents who reported previous experience with HIV-positive individuals. Previous experience with HIV-positive individuals was reported by 182 respondents (82.3%).

Table 6 reports the numbers of HIV-positive individuals experienced by these 182 nurses. The number of HIV-positive individuals experienced ranged from one to over 25. The mean number of HIV-positive individuals experienced prior to the distribution of the questionnaire was 9.8 individuals.

Table 1

Age of Respondents

Age Group	<u>N</u>	%
Not Indicated	1	0.4
20 - 29	25	11.2
30 - 39	93	41.5
40 - 49	70	31.3
50 - 59	31	13.8
60+	4	1.8
Total	224	100.0

Table 2

Sex of Respondents

Sex	<u>N</u>	%
Not Indicated	1	0.4
Male	7	3.1
Female	216	96.5
Total	224	100.0

Table 3

Nursing Experience of Respondents

Years Experience	<u>N</u>	%
Not Indicated	1	0.4
0 - 4	21	9.4
5 - 9	38	16.9
10-14	55	24.6
15-19	46	20.5
20-24	32	14.3
25-29	15	6.7
30-34	10	4.5
35-39	4	1.8
40+	2	0.9
Total	224	100.0

Table 4

Education of Respondents

Education	<u>N</u>	%
<hr/>		
Not Indicated	2	0.9
LVN	11	4.9
RN, Diploma	36	16.1
LVN, Associate Degree	8	3.6
RN, Associate Degree	76	33.9
LVN, Baccalaureate Degree	1	0.4
RN, Baccalaureate Degree	76	33.9
RN, Master's Degree	14	6.3
<hr/>		
Total	224	100.0
<hr/>		

Table 5

Previous Experience With HIV-Positive Individuals

Experience	<u>N</u>	%
Not Indicated	3	1.3
Without Previous Experience	39	17.4
With Previous Experience	182	81.3
Total	224	100.0

Table 6

Numbers of HIV-Positive Individuals Experienced

HIV-Positive	<u>N</u>	%
1 - 4	57	31.3
5 - 9	46	25.3
10 - 14	41	22.5
15 - 19	16	8.8
20 - 24	8	4.4
25+	14	7.7
Total	182	100.0

Analysis of Data

Results of the Knowledge Assessment

Part two of the data collection instrument was a ten-item true/false test which measured nurse knowledge concerning AIDS. Table 7 represents the scores by respondents on the knowledge, attitudes, and willingness to interact assessment tools. The range of scores on the knowledge assessment tool was from 4 to 10 (mean of 8.3). The maximum score possible was ten. The range of scores on the attitude assessment tool was from 26 to 60 (mean of 51.6). The maximum score possible was 60. Finally, the range of scores on the willingness to interact tool was 7 to 35 (mean of 29.8). The maximum score possible was 35. The attitude and willingness to interact scores will be discussed subsequently.

Table 7

Knowledge, Attitude, and Willingness Scores (N = 224)

Item	<u>M</u>	Range	Total Possible
Knowledge	8.3	4 - 10	10
Attitude	51.6	26 - 60	60
Willingness	29.8	7 - 35	35

Table 8 represents the scores on each item of the knowledge assessment. A high number of respondents correctly answered questions concerning the availability of a vaccine (99.6%), prevention (99.1%), transmission (98.7%), lack of transmission through casual contact (98.2%), the role of each individual in preventing the spread of infection (96.9%), and the need for the general public to be concerned about AIDS (92.9%). Accurate knowledge of the risk of infection from transfusion was demonstrated by 89.8% in response to the question, "There is a high risk of acquiring AIDS from a transfusion."

"Little is actually known about AIDS" is a false statement. Much is actually known about AIDS according to the San Francisco AIDS Foundation (1986). One-hundred seventy-eight respondents correctly answered this question (79.5%).

Only 121 respondents correctly answered the question concerning the appropriate use of the HIV antibody test in diagnosing AIDS (54.1%). The statement, "There is a simple, single test to diagnose AIDS" is false according to the San Francisco AIDS Foundation (1986). While the HIV antibody test is part of the laboratory data which can be used to support a definitive diagnosis of AIDS (Appendix C), it alone is not diagnostic of the clinical condition known as AIDS.

The fewest correct answers were in response to the

question, "There is no end to this health crisis in sight." This statement is false according to the San Francisco Foundation (1986). With increased public awareness about the cause and transmission of AIDS, the spread of the disease can be controlled. Fifty-seven out of 224 respondents (25.5%) correctly answered this question.

This group of nurses demonstrated a mean knowledge assessment score of 8.3 out of 10 possible points indicating a high level of knowledge concerning AIDS. However, this group demonstrated knowledge deficits about AIDS in the following areas: (a) AIDS is preventable and the epidemic potentially controllable, (b) AIDS is not diagnosed solely through the use of the HIV antibody test, and (c) much information exists concerning AIDS.

Table 8

Correct Responses To Knowledge Assessment Items

Question	<u>N</u>	%
There is a vaccine	223	99.6
AIDS can be prevented	222	99.1
Anyone can contract/transmit	221	98.7
Spread through casual contact	220	98.2
Little an individual can do	217	96.9
General public should not be concerned about AIDS	208	92.9
High risk from transfusions	201	89.8
Little is known about AIDS	178	79.5
Simple, single diagnostic test	121	54.1
No end to this health crisis	57	25.5

Results of the Attitudes Assessment

Part three of the data collection instrument was a 12-item Prejudicial Evaluation Scale which measured attitudes of nurses towards individuals with AIDS. Table 7 represents the scores from this scale. Scores ranged from 26 to 60 with a mean attitude score of 51.6. The mean score per item on the attitude assessment is shown in Table 9. The two lowest scores on the Likert scale were assigned to more negative or harsh respondent attitudes. Consequently, a mean score per item of 1.0 to 2.9 measured more negative or harsh respondent attitudes. The median score on the Likert scale was assigned to equivocal respondent attitudes. Consequently, a mean score per item of 3.0 to 3.9 measured equivocal respondent attitudes. The two highest scores on the Likert scale were assigned to more positive or supportive respondent attitudes. Consequently a mean score per item of 4.0 to 5.0 measured positive or supportive attitudes.

The majority of scores on the Prejudicial Evaluation Scale indicated the presence of positive, supportive attitudes towards clients with AIDS. The only negative or harsh attitudes were measured in response to item one, "Mark is responsible for his illness" (mean 2.9). Respondents agreed that Mark was responsible for the acquisition of his viral infection. The vignette did not provide information to support this attitude.

Respondents were equivocal in their response to item five, "Mark is dangerous to others" (mean 3.7). The remainder of the 12 items measured had mean scores of between 4.3 and 4.7 indicating positive or supportive respondent attitudes. Respondents agreed with items 2, 4, 6, and 7 which indicated that Mark deserved sympathy and understanding, that he had lots of pain and suffering, that his disease had been traumatic for him, and that Mark deserved the best medical care possible. The respondents demonstrated positive or supportive attitudes by their disagreement with items 3, 8, 9, 10, 11, and 12 which indicated that Mark deserved what happened to him, that he deserved to die, that the world would be better off without him, that suicide was his best solution, that he should be quarantined, and that he deserves to lose his job.

Summary

The majority of the scores on the Prejudicial Evaluation Scale indicated the presence of positive, supportive attitudes towards clients with AIDS. The mean points scored out of 60 possible points was 51.6 with a range of 26 to 60 as shown in Table 7. Though the vignette did not provide any information about Mark's knowledge of HIV transmission, prevention, or any attendant risk behaviors, respondents demonstrated negative, harsh attitudes concerning Mark's responsibility in acquiring his infection (mean 2.9). Though the vignette did not provide

any information about Mark's practice of safer sex, respondents demonstrated equivocal attitudes on item five concerning Mark's danger to others (mean 3.7). Respondents demonstrated positive, supportive attitudes on the remainder of the Prejudicial Evaluation Scale (means of 4.3 to 4.7).

Table 9

Attitude Assessment Items:
Prejudicial Evaluation Scale

Item No.	Item	<u>M</u>
1	Responsible for his illness	2.9
2	Deserves understanding	4.3
3	Deserves what has happened	4.4
4	Lots of pain and suffering	4.4
5	Dangerous to others	3.7
6	Traumatic for him	4.6
7	Deserves the best medical care possible	4.6
8	Deserves to die	4.7
9	World better off without him	4.6
10	Suicide is his best solution	4.3
11	Should be quarantined	4.5
12	Deserves to lose his job	4.6

Note:

4.0 - 5.0 = Positive, supportive attitudes

3.0 - 3.9 = Equivocal attitudes

1.0 - 2.9 = Negative, harsh attitudes

Results of the Willingness

To Interact Assessment

Part five of the data collection instrument was a seven-item Social Interaction Scale which measured the willingness of nurses to interact with the individual with AIDS (see Appendix B). Table 10 represents the scores from this scale. Respondents were more willing to interact with the individual with AIDS in items 1, 2, 4, 5, 6 and 7 by engaging in conversation, attending a party where he would be present, working in the same office, continuing a friendship at the time of the individual's illness, as a landlord renewing his lease in spite of his illness, and allowing children to visit with the individual in his home (means 4.2 - 4.5). Respondents were equivocal in their response to item three, "Would you attend a party where Mark was preparing food" (mean 3.7).

Table 10

Results of the Willingness To Interact Items:
The Social Interaction Scale

Item No.	Item	<u>M</u>
1	Willing to engage in conversation	4.4
2	Willing to attend a party	4.4
3	Willing to attend party with food	3.7
4	Willing to work in same office	4.4
5	Willing to continue friendship	4.5
6	Willing to renew lease	4.4
7	Willing to allow children to visit	4.2

Note:

4.0 - 5.0 = More Willing To Interact

3.0 - 3.9 = Equivocal Responses

1.0 - 2.9 = Less Willing To Interact

Results of the Correlation Analysis

The final part of the analysis were the correlations of (a) knowledge with willingness to interact, (b) attitudes with willingness to interact, and (c) knowledge plus attitudes with willingness to interact.

Knowledge and Willingness

Using the respondents' knowledge scores as the independent x variable and their willingness to interact scores as the dependent y variable, the Pearson product moment correlation coefficient (Pearson's r) was used to examine their relationship. Table 11 represents the results of this correlation analysis. The calculated value of r for the correlation of knowledge and willingness to interact with individuals with AIDS was .0942, indicating a small, positive correlation between knowledge and willingness to interact. However, this r value is not statistically significant (Weinberg & Schumaker, 1974). Thus, knowledge has a positive but nonsignificant correlation with these nurses' willingness to interact with the portrayed client with AIDS. Therefore, the first hypothesis, the positive relationship of knowledge and willingness was not supported.

Attitudes and Willingness

Using the respondents' attitude scores as the Table 11 independent x variable and their willingness to interact scores as the dependent y variable, Pearson's r was used to

examine these variables for any correlation. Table 11 represents the results of this correlation analysis. The correlation of attitude and willingness to interact was .7297. This r value is statistically significant ($p < .01$), supporting the second hypothesis of this thesis, a positive correlation between attitude and willingness to interact. That is, the higher a nurses' attitude, the higher the willingness to interact.

Knowledge and Attitudes with Willingness

By summing the respondents' knowledge and attitude scores as the independent x variable and using their willingness to interact scores as the dependent y variable, Pearson's r was used to examine the variables for correlation. Table 11 represents the results of this correlation analysis. The correlation of knowledge plus attitude with willingness was .4538. This r value is statistically significant ($p < .05$) and supports the third hypothesis, the positive correlation of knowledge and attitude with willingness. That is, the higher the knowledge and attitude, the higher (greater) the willingness to interact with clients with AIDS.

Table 11

Correlational Analyses (N = 224)

Variable	<u>r</u>
Knowledge with Willingness	.09
Attitude with Willingness	.73 **
Knowledge + Attitude with Willingness	.45 *

Note:

* statistically significant ($p < .05$)

** statistically significant ($p < .01$)

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

This study examined the correlations between three independent variables (a) knowledge, (b) attitudes, and (c) knowledge plus attitudes and the dependent variable, willingness to interact with and care for clients with AIDS. This chapter contains the summary, conclusions, and recommendations for educational programs and further research.

Summary

This study design used survey methods and correlational analysis. The sample for this study included 224 employed registered nurses and licensed vocational nurses. The typical respondent was fairly young (mean age of 39.6 years), female (96.5%), experienced in nursing (mean of 15.3 years), with prior experience with HIV-positive individuals (81.3% of respondents reported experience with a mean of 9.8 individuals).

The data collection instrument consisted of five parts: (a) demographic information, (b) AIDS knowledge assessment, (c) a vignette portraying an individual who developed AIDS, (d) an attitudes assessment in response to the vignette, and (e) a willingness to interact with the individual with AIDS assessment, also in response to the vignette.

Results include the respondents' knowledge about AIDS, attitudes toward clients with AIDS, and their willingness to

interact with and care for clients with AIDS. The findings from the data collection instruments indicate a fairly high level of knowledge about AIDS (mean of 8.3), positive, supportive attitudes towards clients with AIDS (mean of 51.6), and a high willingness to interact with the portrayed individual with AIDS (mean of 29.8).

Knowledge deficits were identified in the following areas: (a) AIDS is preventable and the epidemic potentially controllable, (b) AIDS is not diagnosed solely through the use of the HIV antibody test, and (c) much information is known and available concerning AIDS. A negative or harsh attitude identified was that individuals with AIDS are responsible for acquiring their viral infection, although respondents did not feel that the individual deserved negative sequelae as a result of this infection. Equivocal responses were elicited regarding the danger of an individual with AIDS to others. While respondents were generally very willing to interact with the individual with AIDS, equivocal responses were ascertained regarding their willingness to attend a party where the individual with AIDS was preparing food.

A statistically insignificant, positive correlation was found between nurses' knowledge about AIDS and their willingness to interact with individuals with AIDS. A statistically significant positive correlation was found between nurses' attitudes and their willingness to interact

with individuals with AIDS ($r = .7297$, $p < .01$). A second statistically significant positive correlation was found between knowledge plus attitude and the willingness to interact with individuals with AIDS ($r = .4538$, $p < .05$).

Conclusions

In the presence of a viral pandemic which is considered universally fatal and for which there is no cure at this point in time, education about prevention behavior is critical. Indeed, education about AIDS prevention has been recommended as the only effective tool in stopping the spread of the infection. However, it is critical that the education provided be the most effective education possible. Effective AIDS education is education which results in the utilization of prevention behaviors by all members of the population with risk behaviors, and the performance of willing, safe, interactive behaviors by health care professionals.

In the sample studied, knowledge about AIDS had a small positive correlation which was not significant. However, attitude had a significant positive correlation. This result is important to AIDS education curricula for nurses and, ultimately, in the reduction of fear-oriented behavior or even treatment refusals by nurses when asked to interact with and care for clients with AIDS. As shown by these results, knowledgeable nurses may still be less willing or unwilling to interact with or provide care to clients with

AIDS. Further, nurses with positive, supportive attitudes are more willing to interact with and provide the care which clients with AIDS so desperately need as this epidemic continues.

Findings from this study regarding the nurses' perception that individuals with AIDS are responsible for their illness support the findings of Katz, et al. (1987). Findings from this study regarding the greater impact of nurses' attitudes over nurses' knowledge about AIDS in preparing nurses to care for individuals with AIDS support the work done by McCutchan (1986) and later by Kennedy (1987). Kennedy (1987) found that health care workers must confront their own fears before they can support a client with AIDS.

It would seem clear that AIDS is laden with many issues outside the cognitive realm of knowledge. Such issues need to be addressed in providing effective AIDS education in order for nurses to be willing to interact with and care for clients with AIDS. By providing effective AIDS education, the needs created by this health crisis may be met while preventing demoralization and possibly diminution of the numbers of nurses willing to practice nursing in the presence of an otherwise lethal infection within the health care setting.

Recommendations

The following recommendations are made based upon the findings of this study:

1. The results support the importance of attitudes in producing an outcome that is favorable to the quality of care of clients with AIDS (namely, that attitudes of nurses are significant variables in predicting whether or not a nurse will be willing to provide care to a client with AIDS). Nursing education about AIDS should be broadened from the cognitive domain of knowledge, to the affective domain involving belief, attitude, intention, and ultimately, behavior. If further research supports these findings, current nursing AIDS education programs should be evaluated and revised to include exploration of attitudes of nurses toward factors involved in the transmission of AIDS (i.e., attitudes toward intravenous drug use, homosexuality, and fear of death).

Strategies for implementing nursing education should be evaluated and consideration given to utilizing community resources such as people infected with HIV as guest speakers in order to facilitate the nurse's process of attitude exploration and ultimately understanding in the absence of harsh, judgmental attitudes which may unfavorably affect willingness to interact. Other teaching strategies which facilitate interactive discussion by participants should be emphasized and didactic discourse deemphasized

when teaching the subject of AIDS effectively in order to allow student attitudes to surface, to be explored (i.e., through role play, opinion polls), and to be adequately discussed in a supportive environment.

2. In AIDS education programs, curricula should correct the knowledge deficits demonstrated by this study population through effective education followed by evaluation. Educational content should include the concept that AIDS is preventable and the epidemic potentially preventable. Further, the appropriate use of the HIV antibody test and correct methods to diagnosis AIDS should be reviewed. Emphasis should be placed upon the quantity and quality of knowledge about AIDS which is currently available.

3. Educational changes made should be evaluated and reported where significant in order for the most effective teaching methods to be available as soon as possible to the nursing education community.

4. This research should be replicated in a wider geographic area with other nurses/health care workers. The results concerning the attitudes of nurses and their willingness to interact with and care for clients with AIDS are significant. The study is limited due to the single hospital nursing population studied and the potential of the respondents to answer with socially acceptable questionnaire responses.

Concluding Statement

AIDS is a major pandemic which has resulted in the death of thousands of people in the United States alone. Nurses in the health care setting are likely to come into increasing contact with clients with this infection. For these clients to receive quality care, the nurse must be willing to overcome any fears of infection or death, as well as negative, judgmental attitudes regarding intravenous drug use or homosexuality which may lead to an unwillingness to interact with the client with AIDS.

Providing education to the public and to health care workers has been nationally recognized as the only effective method of preventing HIV infection and controlling the epidemic. Effective education allows the nurse to process such fears and attitude-driven behaviors. Otherwise, as was shown by Rosendorf (1984), education may produce only a knowledgeable but frightened individual who remains unwilling to interact fully with clients with AIDS or who may even refuse to provide care. In order to successfully meet the complex needs of clients infected with HIV and facilitate health care delivery in an efficient and cost-effective manner, effective nursing education must first be provided. This research suggests that the development of non-judgmental, supportive attitudes increases the probability of nurses' willingness to care for clients with AIDS.

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APPENDIX A
Consent Letter

AGREEMENT TO PARTICIPATE IN RESEARCH
AT
SAN JOSE STATE UNIVERSITY

RESPONSIBLE INVESTIGATOR: Patti Emmett, RN, BS

TITLE OF PROTOCOL: The Relationship Between The Nurses' Knowledge, Attitude, And Willingness To Interact With Clients With Acquired Immune Deficiency Syndrome (AIDS).

I have been asked to participate in a study that is investigating perceptions about AIDS. The results will be used for designing AIDS education.

I understand that

- 1) I will be asked to complete a questionnaire survey which takes approximately 10 minutes.
- 2) there are no risks or discomforts associated with completing this questionnaire survey.
- 3) the possible benefit of this study to me is my contribution toward AIDS education. I understand that I will receive no monetary reward for my participation in this questionnaire survey.
- 4) I understand that there are no other alternative procedures available to me to allow survey participation other than the written questionnaire.
- 5) the results from this study may be published, but my individual anonymity is assured as my response will be combined with those of 373 other nurses. Individual responses are strictly confidential.
- 6) any questions about my participation in this questionnaire survey will be answered by Patti Emmett at (408) 484-1330. Complaints about the questionnaire survey may be presented to Dr. Colleen Saylor, SJSU, (408) 924-3157. For questions or complaints about my rights, I can contact Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies at (408) 924-2480.
- 7) my consent is given voluntarily without being coerced; I may refuse to participate in this study or in any part of this study, and I may withdraw at any time, without prejudice to my relations with Community Hospital of the Monterey Peninsula or San Jose State University.

- 8) by returning the questionnaire, I have given my consent to participate in the questionnaire survey and that this form is for my files.

APPENDIX B
Data Collection Form

Dear Staff,

I am requesting your assistance in gathering data for the completion of my thesis for the Master's Degree program at San Jose State University.

Please read and complete Parts I and II of the enclosed survey. Then, after reading the vignette about "Mark", please complete Parts III and IV. The survey takes approximately ten minutes to complete.

The survey should be returned as soon as possible and no later than two weeks after receipt in the enclosed envelope. Return the envelope via the interdepartmental outgoing mail to the Education Department, or tube the envelope to Tube Station D-6 (Education Department).

For further information concerning your rights as a human research subject, please refer to the "Agreement To Participate in Research at San Jose State University" attached to this letter.

I thank you kindly for your very important contribution to my research.

Sincerely,

Patti Emmett, RN, BS

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These consist of pages:

63-68, Part I-Part IV

U·M·I

APPENDIX C
Revised Centers For Disease Control
Case Definition of AIDS

Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome

*Reported by
Council of State and Territorial Epidemiologists;
AIDS Program, Center for Infectious Diseases, CDC*

INTRODUCTION

The following revised case definition for surveillance of acquired immunodeficiency syndrome (AIDS) was developed by CDC in collaboration with public health and clinical specialists. The Council of State and Territorial Epidemiologists (CSTE) has officially recommended adoption of the revised definition for national reporting of AIDS. The objectives of the revision are a) to track more effectively the severe disabling morbidity associated with infection with human immunodeficiency virus (HIV) (including HIV-1 and HIV-2); b) to simplify reporting of AIDS cases; c) to increase the sensitivity and specificity of the definition through greater diagnostic application of laboratory evidence for HIV infection; and d) to be consistent with current diagnostic practice, which in some cases includes presumptive, i.e., without confirmatory laboratory evidence, diagnosis of AIDS-indicative diseases (e.g., *Pneumocystis carinii* pneumonia, Kaposi's sarcoma).

The definition is organized into three sections that depend on the status of laboratory evidence of HIV infection (e.g., HIV antibody) (Figure 1). The major proposed changes apply to patients with laboratory evidence for HIV infection: a) inclusion of HIV encephalopathy, HIV wasting syndrome, and a broader range of specific AIDS-indicative diseases (Section II.A); b) inclusion of AIDS patients whose indicator diseases are diagnosed presumptively (Section II.B); and c) elimination of exclusions due to other causes of immunodeficiency (Section I.A).

Application of the definition for children differs from that for adults in two ways. First, multiple or recurrent serious bacterial infections and lymphoid interstitial pneumonia/pulmonary lymphoid hyperplasia are accepted as indicative of AIDS among children but not among adults. Second, for children <15 months of age whose mothers are thought to have had HIV infection during the child's perinatal period, the laboratory criteria for HIV infection are more stringent, since the presence of HIV antibody in the child is, by itself, insufficient evidence for HIV infection because of the persistence of passively acquired maternal antibodies < 15 months after birth.

The new definition is effective immediately. State and local health departments are requested to apply the new definition henceforth to patients reported to them. The initiation of the actual reporting of cases that meet the new definition is targeted for September 1, 1987, when modified computer software and report forms should be in place to accommodate the changes. CSTE has recommended retrospective application of the revised definition to patients already reported to health departments. The new definition follows:

1987 REVISION OF CASE DEFINITION FOR AIDS FOR SURVEILLANCE PURPOSES

For national reporting, a case of AIDS is defined as an illness characterized by one or more of the following "indicator" diseases, depending on the status of laboratory evidence of HIV infection, as shown below.

I. Without Laboratory Evidence Regarding HIV Infection

If laboratory tests for HIV were not performed or gave inconclusive results (See Appendix I) and the patient had no other cause of immunodeficiency listed in Section I.A below, then any disease listed in Section I.B indicates AIDS if it was diagnosed by a definitive method (See Appendix II).

A. Causes of immunodeficiency that disqualify diseases as indicators of AIDS in the absence of laboratory evidence for HIV infection

1. high-dose or long-term systemic corticosteroid therapy or other immunosuppressive/cytotoxic therapy ≤ 3 months before the onset of the indicator disease
2. any of the following diseases diagnosed ≤ 3 months after diagnosis of the indicator disease: Hodgkin's disease, non-Hodgkin's lymphoma (other than primary brain lymphoma), lymphocytic leukemia, multiple myeloma, any other cancer of lymphoreticular or histiocytic tissue, or angioimmunoblastic lymphadenopathy
3. a genetic (congenital) immunodeficiency syndrome or an acquired immunodeficiency syndrome atypical of HIV infection, such as one involving hypogammaglobulinemia

B. Indicator diseases diagnosed definitively (See Appendix II)

1. candidiasis of the esophagus, trachea, bronchi, or lungs
2. cryptococcosis, extrapulmonary
3. cryptosporidiosis with diarrhea persisting >1 month
4. cytomegalovirus disease of an organ other than liver, spleen, or lymph nodes in a patient >1 month of age
5. herpes simplex virus infection causing a mucocutaneous ulcer that persists longer than 1 month; or bronchitis, pneumonitis, or esophagitis for any duration affecting a patient >1 month of age
6. Kaposi's sarcoma affecting a patient < 60 years of age
7. lymphoma of the brain (primary) affecting a patient < 60 years of age
8. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child < 13 years of age
9. *Mycobacterium avium* complex or *M. kansasii* disease, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. *Pneumocystis carinii* pneumonia
11. progressive multifocal leukoencephalopathy
12. toxoplasmosis of the brain affecting a patient >1 month of age

II. With Laboratory Evidence for HIV Infection

Regardless of the presence of other causes of immunodeficiency (I.A), in the presence of laboratory evidence for HIV infection (See Appendix I), any disease listed above (I.B) or below (II.A or II.B) indicates a diagnosis of AIDS.

A. Indicator diseases diagnosed definitively (See Appendix II)

1. bacterial infections, multiple or recurrent (any combination of at least two within a 2-year period), of the following types affecting a child < 13 years of age:

septicemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses), caused by *Haemophilus*, *Streptococcus* (including pneumococcus), or other pyogenic bacteria

2. coccidioidomycosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
3. HIV encephalopathy (also called "HIV dementia," "AIDS dementia," or "subacute encephalitis due to HIV") (See Appendix II for description)
4. histoplasmosis, disseminated (at a site other than or in addition to lungs or cervical or hilar lymph nodes)
5. isosporiasis with diarrhea persisting >1 month
6. Kaposi's sarcoma at any age
7. lymphoma of the brain (primary) at any age
8. other non-Hodgkin's lymphoma of B-cell or unknown immunologic phenotype and the following histologic types:
 - a. small noncleaved lymphoma (either Burkitt or non-Burkitt type) (See Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases*, Ninth Revision, Clinical Modification)
 - b. immunoblastic sarcoma (equivalent to any of the following, although not necessarily all in combination: immunoblastic lymphoma, large-cell lymphoma, diffuse histiocytic lymphoma, diffuse undifferentiated lymphoma, or high-grade lymphoma) (See Appendix IV for equivalent terms and numeric codes used in the *International Classification of Diseases*, Ninth Revision, Clinical Modification)

Note: Lymphomas are not included here if they are of T-cell immunologic phenotype or their histologic type is not described or is described as "lymphocytic," "lymphoblastic," "small cleaved," or "plasmacytoid lymphocytic"

9. any mycobacterial disease caused by mycobacteria other than *M. tuberculosis*, disseminated (at a site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
10. disease caused by *M. tuberculosis*, extrapulmonary (involving at least one site outside the lungs, regardless of whether there is concurrent pulmonary involvement)
11. *Salmonella* (nontyphoid) septicemia, recurrent
12. HIV wasting syndrome (emaciation, "slim disease") (See Appendix II for description)

B. Indicator diseases diagnosed presumptively (by a method other than those in Appendix II)

Note: Given the seriousness of diseases indicative of AIDS, it is generally important to diagnose them definitively, especially when therapy that would be used may have serious side effects or when definitive diagnosis is needed

for eligibility for antiretroviral therapy. Nonetheless, in some situations, a patient's condition will not permit the performance of definitive tests. In other situations, accepted clinical practice may be to diagnose presumptively based on the presence of characteristic clinical and laboratory abnormalities. Guidelines for presumptive diagnoses are suggested in Appendix III.

1. candidiasis of the esophagus
2. cytomegalovirus retinitis with loss of vision
3. Kaposi's sarcoma
4. lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia (LIP/PLH complex) affecting a child <13 years of age
5. mycobacterial disease (acid-fast bacilli with species not identified by culture), disseminated (involving at least one site other than or in addition to lungs, skin, or cervical or hilar lymph nodes)
6. *Pneumocystis carinii* pneumonia
7. toxoplasmosis of the brain affecting a patient >1 month of age

III. With Laboratory Evidence Against HIV Infection

With laboratory test results negative for HIV infection (See Appendix I), a diagnosis of AIDS for surveillance purposes is ruled out *unless*:

- A. all the other causes of immunodeficiency listed above in Section I.A are excluded; AND
- B. the patient has had either:
 1. *Pneumocystis carinii* pneumonia diagnosed by a definitive method (See Appendix II); OR
 2. a. any of the other diseases indicative of AIDS listed above in Section I.B diagnosed by a definitive method (See Appendix II); AND
b. a T-helper/inducer (CD4) lymphocyte count <400/mm³.

COMMENTARY

The surveillance of severe disease associated with HIV infection remains an essential, though not the only, indicator of the course of the HIV epidemic. The number of AIDS cases and the relative distribution of cases by demographic, geographic, and behavioral risk variables are the oldest indices of the epidemic, which began in 1981 and for which data are available retrospectively back to 1978. The original surveillance case definition, based on then-available knowledge, provided useful epidemiologic data on severe HIV disease (1). To ensure a reasonable predictive value for underlying immunodeficiency caused by what was then an unknown agent, the indicators of AIDS in the old case definition were restricted to particular opportunistic diseases diagnosed by reliable methods in patients without specific known causes of immunodeficiency. After HIV was discovered to be the cause of AIDS, however, and highly sensitive and specific HIV-antibody tests became available, the spectrum of manifestations of HIV infection became better defined, and classification systems for HIV infection were developed (2-5). It became apparent that some progressive, seriously disabling, and even fatal conditions (e.g., encephalopathy, wasting syndrome) affecting a substantial number of HIV-infected patients were not subject to epidemiologic surveillance, as they were not included in the AIDS

case definition. For reporting purposes, the revision adds to the definition most of those severe non-infectious, non-cancerous HIV-associated conditions that are categorized in the CDC clinical classification systems for HIV infection among adults and children (4,5).

Another limitation of the old definition was that AIDS-indicative diseases are diagnosed presumptively (i.e., without confirmation by methods required by the old definition) in 10%-15% of patients diagnosed with such diseases; thus, an appreciable proportion of AIDS cases were missed for reporting purposes (6,7). This proportion may be increasing, which would compromise the old case definition's usefulness as a tool for monitoring trends. The revised case definition permits the reporting of these clinically diagnosed cases as long as there is laboratory evidence of HIV infection.

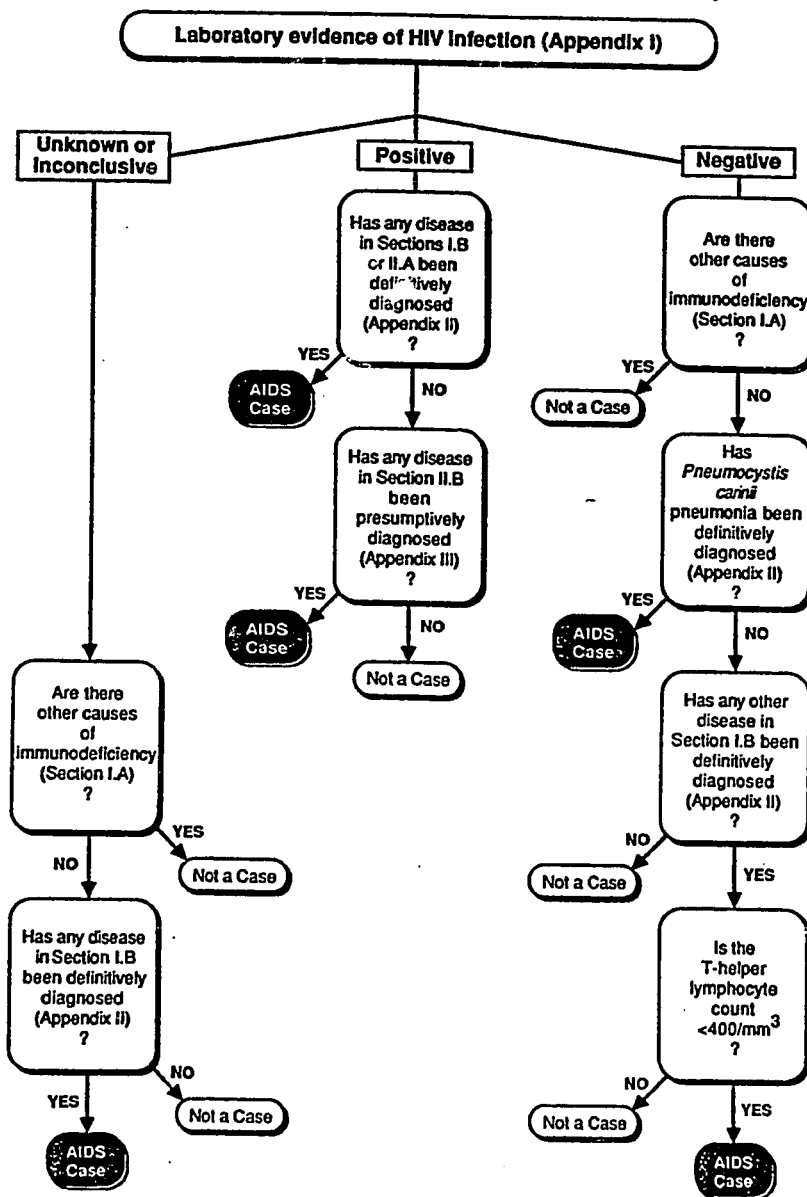
The effectiveness of the revision will depend on how extensively HIV-antibody tests are used. Approximately one third of AIDS patients in the United States have been from New York City and San Francisco, where, since 1985, < 7% have been reported with HIV-antibody test results, compared with > 60% in other areas. The impact of the revision on the reported numbers of AIDS cases will also depend on the proportion of AIDS patients in whom indicator diseases are diagnosed presumptively rather than definitively. The use of presumptive diagnostic criteria varies geographically, being more common in certain rural areas and in urban areas with many indigent AIDS patients.

To avoid confusion about what should be reported to health departments, the term "AIDS" should refer only to conditions meeting the surveillance definition. This definition is intended only to provide consistent statistical data for public health purposes. Clinicians will not rely on this definition alone to diagnose serious disease caused by HIV infection in individual patients because there may be additional information that would lead to a more accurate diagnosis. For example, patients who are not reportable under the definition because they have either a negative HIV-antibody test or, in the presence of HIV antibody, an opportunistic disease not listed in the definition as an indicator of AIDS nonetheless may be diagnosed as having serious HIV disease on consideration of other clinical or laboratory characteristics of HIV infection or a history of exposure to HIV.

Conversely, the AIDS surveillance definition may rarely misclassify other patients as having serious HIV disease if they have no HIV-antibody test but have an AIDS-indicative disease with a background incidence unrelated to HIV infection, such as cryptococcal meningitis.

The diagnostic criteria accepted by the AIDS surveillance case definition should not be interpreted as the standard of good medical practice. Presumptive diagnoses are accepted in the definition because not to count them would be to ignore substantial morbidity resulting from HIV infection. Likewise, the definition accepts a reactive screening test for HIV antibody without confirmation by a supplemental test because a repeatedly reactive screening test result, in combination with an indicator disease, is highly indicative of true HIV disease. For national surveillance purposes, the tiny proportion of possibly false-positive screening tests in persons with AIDS-indicative diseases is of little consequence. For the individual patient, however, a correct diagnosis is critically important. The use of supplemental tests is, therefore, strongly endorsed. An increase in the diagnostic use of HIV-antibody tests could improve both the quality of medical care and the function of the new case definition, as well as assist in providing counselling to prevent transmission of HIV.

FIGURE I. Flow diagram for revised CDC case definition of AIDS, September 1, 1987



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